

Need of comprehensive health care for *T. cruzi* infected immigrants in Europe

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ABSTRACT

Paleoparasitology studies have evidenced that Chagas disease is almost as old as man's presence in the Americas. At the beginning of the twentieth century the disease was mostly confined to the rural areas of South America, Central America and Mexico. Later, the increase of population mobility, facilitated by the new different means of transport, greatly contributed to spread the disease and even the vector first across Latin America, secondly to the urban and peri-urban environment, and finally to the so-called disease non-endemic countries. Consequently, new areas harbouring people with *T. cruzi* infection have faced the risk of autochthonous transmission. Since the last decade of the twentieth century, Chagas disease has become an emerging public health challenge in Europe. This challenge stems from the considerable diversity observed among Latin American immigrants: a variety of origins and social groups; a heterogeneous geographical distribution in the continent; a wide range in their prevalence rates of *T. cruzi* infection; and different predominance of clinical forms of the chronic phase and different severity of morbidity. The identification of the main health determinants of the Latin American immigrant communities in a specific area (including their diversity and barriers such as their immigrant condition and their socio-cultural-economic characteristics) is crucial to design and implement comprehensive health-care strategies for the care of people with Chagas disease in Europe. Specific innovative approaches are needed to make possible the meeting between the health system and the *T. cruzi* infected patients, such as: the multidisciplinary approach; the community approach; and the Expert Patient Programme. The associations of Chagas disease patients have also been proven to be very helpful as voice of these usually neglected patients.

Key-words: Comprehensive health care. Immigrants. Europe. Disease non-endemic. *T. cruzi* infection. Chagas disease.

HUMAN MOBILITY AND CHAGAS DISEASE DISTRIBUTION IN THE WORLD

According to one of the most accepted hypothesis, America was first settled by people from Asia who migrated across the Bering Strait around 20.000-25.000 years ago¹. It is believed that groups of this early population migrated from North America to South America, on foot or using primitive boats along the coastline approximately 12.000-15.000 years ago².

Paleoparasitology studies have evidenced that Chagas disease is almost as old as man's presence in the Americas. At present, the most ancient human infection by *Trypanosoma cruzi* (flagellate protozoa of the kinetoplastida order and trypanosomatidae family), is known from mummies dated as 9.000 years old and found in the coastal and low valley sites in northern and southern Chile³.

Carlos Ribeiro Justiniano Chagas discovered the disease in 1909 in Brazil. At the beginning of the twentieth century the disease was mostly confined to the rural areas of South America, Central America and Mexico. Later, the population mobility through new transportation routes, especially railroads and roadways, greatly contributed to disseminate the disease across 21 Latin American countries (Argentina, Belize, Bolivia, Brazil, Chile, Colombia, Ecuador, French Guiana, Guyana, Paraguay, Peru, Uruguay, Suriname and Venezuela, in South America; Costa Rica, El Salvador, Guatemala, Honduras, Nicaragua, Panama, in Central America; and Mexico, in North America). Afterwards, in the second half of the twentieth century, driven by population's flows from the countryside to the cities and also, in some cases, with the adaptation of some vectors to the urban and peri-urban environment, Chagas disease became an urban phenomenon^{4,5}.

At present, Chagas disease can also be found in the so called disease non-endemic countries as a result of the population mobility, mainly migrations occurred in the last decades from Latin American countries where Chagas disease is endemic to the USA, Canada, many European countries (especially Belgium, France, Italy, Spain, Switzerland and the United Kingdom, but also Austria, Croatia, Denmark, Germany, Luxembourg, the Netherlands, Norway, Portugal, Romania and Sweden) and some Western Pacific countries (mainly Australia and Japan). Additionally, the disease expansion outside Latin America has also been associated to foreigners visiting disease-endemic areas, for work or tourism reasons, and returning to their home countries infected by *T. cruzi*. Consequently, countries harbouring people with *T. cruzi* infection face the risk of autochthonous transmission through blood transfusion, transmission from mother to son infection (vertical) and through organ transplantation^{6,7}.

INITIAL SPREAD OF CHAGAS DISEASE VECTORS LINKED TO THE POPULATION MOVEMENTS

The vectors of Chagas disease are blood-sucking Hemiptera of the Triatomine subfamily (family Reduviidae). There are more than 140 species of insect vectors of Chagas disease, mainly of American origin. Triatomine bug species with the capacity to transmit *T. cruzi* have also been identified outside America in parts of Africa, Middle East, Southeast Asia and the Western Pacific. Current theories indicate that those species in Southeast Asia have probably derived from American species transported to seaports by sailing ships since the sixteenth century.

The construction of railways and roadways have also played a significant role as means of dispersal for these vectors. There is evidence of the spread of the main intradomestic vector species, the *Triatoma infestans*, from its origin in the Bolivian Andean valleys to the rest of South America. This spread has mainly occurred over

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the last 150 years and it has been associated to human migrations. For example, *T. infestans* has been reported in chairs and passengers' commodities on long-distance trains in Chile during the 1960s, buses in Bolivia during the 1980s, and suitcases of passengers travelling from Bolivia to Argentina in the 1990s⁸.

In addition to maritime and overland routes, at present time, the risk of spreading the Triatomine vector by air transportation routes has also been demonstrated.

CURRENT DIVERSITY OF THE LATIN AMERICAN POPULATION IN EUROPE AT RISK OF BEING INFECTED BY *T. CRUZI*

According to the International Organization for Migration (IOM), Latin American immigrants living in Europe at present are mainly young, at reproductive age and with a high proportion of women⁹. Nevertheless, a considerable diversity has been observed among those Latin American immigrants in Europe at risk of being infected by *T. cruzi*.

The geographical distribution of the Latin American population living in Europe is not homogeneous. For example, according to official sources, Brazilians constitute the largest group of Latin American immigrants in France; Peruvians and Ecuadorians have the highest number of residents in Italy; and Argentineans, Bolivians, Colombians and Ecuadorians have the most significant presence in Spain⁷.

A diversity of social groups has been identified within the Latin American population at risk of being infected in Europe. At country level, one of the most common ways of classifying the immigrant population is according to their legal (documented) or illegal (undocumented) status. For certain European countries, such as France, the groups of adopted children from Latin American countries and children born in France from Latin American mothers, have also been found to be significant in number⁷. Despite the difficulty of the task, it is important to try to obtain accurate estimations of authorized and unauthorized immigrants by country, due to the high estimated proportion of immigrants at risk of having *T. cruzi* infection in Europe.

Prevalence rates for *T. cruzi* infection are also heterogeneous among the Latin American population living in Europe, which reflects geographical variations in the distribution of the infection in their countries of origin. In different studies carried out in European countries, a higher prevalence has been found in the population coming from Latin American regions of high endemicity^{10,11,12,13}, for instance, in the case of Bolivian immigrants who come from Chuquisaca, Cochabamba, Santa Cruz and Tarija Departments.

Moreover, since the 1970s, progressive implementation of various national control programmes in Chagas disease endemic countries, principally focused on eliminating the domestic vectors and establishing blood donation screening for *T. cruzi*, have resulted in a significant reduction of transmission¹³. Therefore, in their countries of origin, older Latin American immigrant generations now living in Europe were often exposed to a higher risk of infection than younger ones. For most of these adult immigrants, their infection occurred decades ago and they are now presumably in the late chronic phase of the disease¹⁴.

Geographical variations in Latin American countries also show different predominance of clinical forms of the chronic phase and different severity of morbidity. Therefore, in the coming years infected

individuals in Europe coming from countries such as Argentina, Bolivia and Brazil may develop myocardiopathy and/or digestive abnormalities, whereas infected people coming from Central American countries may show chronic Chagas cardiopathy without evident digestive abnormalities¹⁵.

EUROPEAN HEALTH SERVICES AND THE NECESSITY OF MEETING HEALTH-CARE NEEDS OF LATIN AMERICAN IMMIGRANTS WITH *T. CRUZI* INFECTION

Until the last decade of the twentieth century, Chagas disease was almost unknown in Europe. At the beginning of the twenty-first century, as an emerging disease, it has represented a big challenge to the health system and society itself. After the first approaches implemented and experiences acquired, a range of challenges involving the care of people with Chagas disease were identified¹⁶:

- Detection of an infection mostly without evident clinical manifestations (asymptomatic);
- Availability of appropriate serological tests for screening and diagnosis purposes and the need of trained health-care professionals able to perform accurate clinical diagnosis;
- Awareness among health and public health professionals about this emerging disease;
- Access to parasitological and non-parasitological treatment; treatment compliance; patient tolerability; patient follow-up; and assessment of therapeutic response;
- Primary prevention of transmission by blood transfusion, cell, tissue or organ transplantation;
- Early diagnosis and treatment (secondary prevention) of congenital transmitted cases;
- Collection and analysis of epidemiological data (baseline) and establishment of an information and surveillance system;
- Understanding and consideration of the complex psycho-social, socio-labour-economic and cultural-linguistic conditions of the Latin American immigrant population in Europe;
- Overcoming the frequently encountered assumption in immigrants from disease endemic countries that adults infected with *T. cruzi* cannot be treated;
- Bridging the gap and creating trust between the health system and communities of documented and especially undocumented immigrants, in order to increase acceptance and adaptation of public health programmes;
- Implementation of public health strategies for the care of people with Chagas disease.

The identification of the main health determinants of the Latin American immigrant communities in a specific area is crucial to design and implement public health strategies for the care of people with Chagas disease in Europe. Among others, some of these health determinants could be their legal and insurance status, cultural and linguistic barriers, their labour conditions and their social-economical situation.

Typically, immigrants in an unauthorized condition have a more limited access to health care. In Switzerland, for example, immigrants

frequently face difficulties in accessing health care because health insurance is expensive. A study conducted in Geneva among 1,012 Latin American immigrants showed that only 4% of the participants had a valid residence permit and health insurance¹¹. Programmes and strategies ensuring that immigrants without documents have access to health care in European countries could improve the health condition of this population¹⁷.

Within the range of challenges regarding access to health care, the utilization of health services by foreign-born communities can be conditioned or influenced by linguistic, cultural or social barriers between these communities and the health-care systems in their host country. It has also been shown that these barriers can be associated with negative health outcomes¹⁷. Consequently, health education and disease prevention activities that are linguistically and culturally tailored for Latin American communities in Europe are needed to ensure the effectiveness of health-care programmes and, ideally, a better use of health services.

Even when immigrants have access to health care and use medical services, the continuity of care can be hampered by the precarious working conditions of immigrants, their frequent geographical mobility and their complex social situations. In a study conducted in Spain between 2004 and 2007, 43/483 (8%) of Latin American adults who attended specialized centres for infectious diseases withdrew from medical care after serological tests had been performed but before specific medical examinations had been conducted¹⁰. The reasons for withdrawal included: conflicting work schedules and health service opening hours; complicated referral arrangements between primary health-care services and medical specialists; and lack of information and sensitization of pregnant Latin American women and their families about the need of diagnosis and treatment^{8,19,20}.

Three innovative methodological approaches have been proposed in order to offer comprehensive health care with a major focus on people in the chronic phase of Chagas disease.

Multidisciplinary approach

A proven successful approach for the care of people with Chagas disease has been the creation of expert teams composed by different professionals, where each member has a distinct role and all members interact with each other in an interdisciplinary process. This professional team will work with close collaboration with the patient and the family (the so-called therapeutic triangle) in order to provide the best health care. It has been shown that the support of the family has a remarkable influence on the adherence to treatment by the patient.

For instance, this professional team can be composed by a diversity of health professionals such as: a cardiologist, who evaluates the patient and advises on the cardiac follow-up and treatment; a nurse, who has frequent contact with the patient and educates him and his family about the disease; a social worker, whose work mainly focuses on minimizing the impact of socio-economic factors on the patient follow-up and his disease; a psychologist, who assesses and counsels on the psycho-emotional factors that are impairing the patient's quality of life; a nutritionist, who, taking into consideration the socio-economic, cultural and environmental background of the patient, designs a feasible diet, thereby facilitating the patient's adherence to the dietary regimen²¹. Primary health-care physicians,

paediatricians, obstetricians, radiologists and gastroenterologists are also key actors to compose the team in order to increase the opportunities to screen and care for infected individuals.

Community approach

In the context of immigration, the meeting between the patient and the health system is only promoted when the condition of the human being and his close family and community links are taken into account (including the immigrant, social, work, language and cultural barriers faced). This meeting between the patient and the health system requires a highly skilled and committed team of health personnel: culturally and professionally diverse and able to work in an interdisciplinary way, as in the above-mentioned approach. The main characteristic of this second approach is the presence of the community health agent as a key member of this team, who is the link between the patient and his family and community, and is a social and political actor with a high capacity of working within the health system and the community.

In the community approach, to better understand the social and cultural diversity of the immigrant population (country of origin, age, gender and others), including their external interactions, it is essential to carry out quantitative and qualitative research that will facilitate the approximation to the reality with its full complexity. The ultimate objective is to create unique strategies to adapt the health system to the needs of the immigrant communities (developing health-care protocols and educational material, among others) and to lower its threshold regarding accessibility (with minimal administrative requests, economically affordable, culture and migrant-friendly and delocalized from main health centres). This will definitely facilitate the implementation of community and family work strategies, with a cross-cultural approach, key to the prevention, diagnosis, treatment and follow-up of infected and ill people^{18,19,20}.

Expert Patient Programme

The recent application of the Expert Patient Programme to Chagas disease is a pioneer methodology because it involves Chagas disease chronically-infected people as active actors in the health-care process. Additionally to medical care, the unique characteristic of this programme is the organization of complementary sessions facilitated by a patient who has first-hand experience in the disease, the "expert patient", who counsels others suffering from similar symptoms and problems. In this approach, the health-care professional attending these sessions has an observer role and can intervene in the session only if requested by the "expert patient"²².

In countries like the United Kingdom this programme has already shown positive effects on the health of people with chronic diseases such as diabetes. At present, a pilot project applying this methodology to Chagas disease patients is being implemented by the Institut Català de la Salut in Barcelona, Catalonia, Spain, in collaboration with the World Health Organization.

The objectives of the Expert Patient Programme for Chagas disease include increasing the knowledge of people with Chagas disease about their condition, improving their degree of self-care, ensuring therapeutic compliance, and improving the quality of their lives and that of their families.

Finally, the authors would like to highlight the current existence of associations of Chagas disease patients in the regions of the

Americas, Europe and the Western Pacific. They have had a key role as voice of the frequently neglected disease carriers. The first assembly of a new International Federation of world associations is being organized in the city of Recife, Pernambuco, Brazil, in the second semester of 2010.

CONCLUSIONS

The comprehensive health care of Chagas disease patients in Europe requires taking into account their significant determinants of health, including their diversity and barriers such as their immigrant condition and their socio-cultural-economic characteristics.

Specific innovative approaches are needed to make possible the meeting between the health system and the *T. cruzi* infected patients, such as: the multidisciplinary approach, with the interaction of several health professionals from different disciplines; the community approach, with the community health agent as a key actor; and the Expert Patient Programme, with the involvement of the patient in his own care. The associations of Chagas disease patients have also been proven to be very helpful as voice of these usually neglected patients.

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